

PALLIATIVE CARE FOR INPATIENTS

PRACTICE GUIDELINE[®]

DOCUMENT SUMMARY/KEY POINTS

- Palliative care encompasses the physical, emotional, psychosocial and spiritual care of the child with a life limiting illness in the context of his or her family.
- Palliative care is flexible and can be provided to children at home, in hospital and at Bear Cottage (hospice) by the Sydney Children's Hospitals Network (SCHN). This includes respite. This practice guideline should be read in conjunction with the [SCHN Palliative Care at Home Practice Guideline](#) and Bear Cottage Policies.
- Provision of competent symptom management for duration of palliative care including end of life care.
- Palliative care is a consultative service that works in conjunction with the primary team for the duration of the child's illness.
- After hours telephone support is available for clinicians caring for a child receiving palliative care.
- Bereavement support services are offered to all families following the death of a child. See [CHW Bereavement Support Practice Guideline](#).

This document reflects what is currently regarded as safe practice. However, as in any clinical situation, there may be factors which cannot be covered by a single set of guidelines. This document does not replace the need for the application of clinical judgement to each individual presentation.

Approved by:	SCHN Policy, Procedure and Guideline Committee	
Date Effective:	1 September 2016	Review Period: 3 years
Team Leader:	Quality Manager	Area/Dept: Pain & Palliative Care Services

CHANGE SUMMARY

The changes include:

- Information about access to the Paediatric Palliative Care (PCC) Statewide After Hours Medical On-Call Service has been included for this document.
- At SCH- the Acute Resuscitation Plan-Paediatrics, is now used to document end of life care planning for children with a life limiting illness (replacing the End of Life Care Plan).
- At CHW-Information has been included about Specialist Paediatric Palliative Care Allied Health staff.
- As a number of changes have been made throughout the document, it is recommended that all users read the entire document.
- Information has been included about Oxycodone/Naloxone (Targin[®]).

READ ACKNOWLEDGEMENT

- All staff working in SPPC Service (SPPC) are to read and acknowledge they understand the contents of this document.
- Other clinical staff are to be aware of this document.

This document reflects what is currently regarded as safe practice. However, as in any clinical situation, there may be factors which cannot be covered by a single set of guidelines. This document does not replace the need for the application of clinical judgement to each individual presentation.

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1 Definitions

The following definitions will be used for the purposes of this document.

Palliative Care

Palliative care is a philosophy of care that is characterised by flexible, family-centred care and support throughout the course of a life limiting illness and continues after the infant, child or young person's death. Palliative care is holistic care that encompasses physical, psychosocial and spiritual care of the child in the context of his or her family. It may be for a few hours or a few years. Although death is the expected and usual outcome, death is not inevitable, particularly in the short term.

The WHO definition of palliative care appropriate for children and their families is as follows; the principles apply to other paediatric chronic disorders(1):

- Palliative care for children is the active total care of the child's body, mind and spirit, and also involves giving support to the family.
- It begins when illness is diagnosed, and continues regardless of whether or not a child receives treatment directed at the disease.
- Healthcare providers' goal is to evaluate and alleviate a child's physical, psychological, and social distress.
- Effective palliative care requires a broad multidisciplinary approach that includes the family and makes use of available community resources; it can be successfully implemented even with limited resources.
- This document refers to palliative care for inpatients however, the SPPC service also supports patient and family care in the community setting to ensure care can be provided at home or as close to home as possible.
- SPPC is consultative, available on both campuses and offers support and guidance to a child's primary care team in the provision of palliative care. It may also provide direct support to the child and family.

Supportive Care

In cases when a decision to refer to palliative care has not yet been reached, the team can provide guidance on symptom and other support.

Child/Children

The term "Child" or "Children" refers to infants, children and young people up to the age of 18 years of age.

SCH

Sydney Children's Hospital, Randwick

CHW

The Children's Hospital at Westmead

SPPC Service (SPPC)

Level 3 tertiary services specialising in paediatric palliative care.

2 Ethical Standards Statement

The principles contained in the RACP's "[Decision Making at the End of Life in Infants, Children & Adolescents - a policy of the Paediatric & Child Health Division of the Royal Australasian College of Physicians](#)" are supported by Specialist Paediatric Palliative Care.

3 Palliative Care for SCHN Patients

The SPPC Services are consultative services that offer support and guidance to a child's primary care team in the provision of palliative care, as well as providing direct support to the child and family. Palliative care services are offered across the spectrum of hospital, home and hospice care.

This document provides guidelines for the management of children receiving support from the SPPC Service as an inpatient of SCHN Randwick or Westmead campuses. Hospice care (respite and/or end of life care) can be provided at Bear Cottage, Manly. See [Section 11](#) for details about Bear Cottage.

For services provided at home, see [SCHN Palliative Care at Home Practice Guideline](#).

4 Criteria for Receiving Palliative Care Services

Criteria for inclusion:

- Children with life limiting illnesses.
- Children for whom a decision has been made to forgo life sustaining treatment.
- Children for whom the primary team require symptomatic advice only (child who may be referred to Palliative Care at a later date).
- Children who have an illness that is not primarily life threatening, e.g. cerebral palsy, but may have concurrent factors that increase their risk. These could include chronic and life threatening respiratory infections or uncontrolled seizures which decrease life expectancy. These children would be considered on an individual basis for access to SPPC services.
- Children who have a diagnosis of a disease where life expectancy is limited but where the child may survive into adulthood. All children will be considered on an individual basis.
- Children who have a high risk of dying but have a potentially curative therapy available (e.g. liver transplant).

If a child is over 16 years of age and up to age of 18 years, but remains within the care of a physician within the SCHN, they will continue to have access to SPPC.

See:

- For SCHN please see [Transitional Care Policy](#).

5 The SPPC Service at SCHN

- The SPPC Service is provided by teams which include:
 - Staff Specialist
 - Fellow
 - Clinical Nurse Consultant
 - Clinical Nurse Specialist
 - Social Worker
 - Bereavement Coordinator
 - Kids Cancer Centre and Blood Disorders or Social Work (SCH)
 - Physiotherapy and Occupational Therapy
 - Clinical Psychology
 - Child Life Therapy (SCH via SPPC Service and CHW via primary team)
 - Non-clinical services - including Quality Manager, Volunteer Coordinator (CHW) and Administration
- As a minimum, families receiving support from the SPPC Service can expect:
 - Comprehensive medical assessment and symptom management
 - Care co-ordination and support regarding treatment goals and plans
 - Psychosocial and financial assessment and support, including links to appropriate services
 - Ongoing home visiting support where possible following discharge from hospital and ongoing email and telephone contact with the family
 - Links to appropriate community services
 - Identification and provision of appropriate emotional, psychosocial and spiritual support
 - Bereavement support following the death of their child (including phone support and/or home visiting and links to appropriate bereavement support)

6 Providing Palliative Care

The SPPC Service aims to support families to look after their child in the location of the family's choice. The provision of palliative care requires:

- Family centred preparation and planning.
- Flexible care arrangements which provide families with the specific support they require to manage a difficult and stressful life experience.

For full details see the [SCHN Palliative Care at Home Practice Guideline](#)

6.1 SPPC Contact Details (Including After-hours)

Staff requiring further information about the SPPC Service at any stage can contact:

- **At CHW:**
 - Page 6794/6322 for the Palliative Care CNC/CNS, Mon-Fri 8am-4.30pm
- **At SCH:**
 - Page 44640 for the Palliative Care Team Mon-Fri 8.30am-5.00pm

After Hours Medical PPC On-Call

After hours support for clinicians managing a child receiving palliative care is via each hospital switchboard

6.2 Referral to the SPPCS

The decision to transition a child from an active treatment focus to a palliative care focus may involve a referral to the SPPC Service. This may entail:

- The consultant or medical officer from the primary team referring patients to the palliative care service. Any member of the palliative care service can be notified of the referral. Urgent referrals will be seen within 24 hours, non-urgent will be seen in liaison with the primary team.
- **At CHW** the Palliative Care Referral Form in Powerchart must be completed following a phone referral.
- **At SCH**, The Palliative Care Consultant, Fellow or Clinical Nurse Consultant must be contacted to discuss the referral. The Universal Paediatric Palliative Care [Referral Form](#) must also be completed.

6.3 Role of Specialist Palliative Care Clinicians in Palliative Care and Family Support

Once the family has accepted the support of the SPPC Service, the clinicians will establish the needs of the child and family, and develop a comprehensive care plan to ensure that those needs are met. **At SCH**, the first meeting is usually with the team member whose expertise the child and family most requires. **At CHW** the first meeting is usually with as many members of the palliative care multi-disciplinary team as possible.

- The initial meeting with the family will serve to:
 - introduce the team
 - explain the meaning of palliative care in the context of their child's illness
 - identify the family's needs and expectations of the team
 - provide the family with contact details and information brochure
 - discuss current symptoms and proposed management
 - explore ways to provide psychosocial /spiritual support
 - liaise with family about engaging community services including community medical/nursing/allied health services
 - determine need for respite services including Bear Cottage
 - Offer provision of a Family Support Volunteer (CHW)
- The following issues around end of life care also need to be considered and based on individual child / family needs or wishes:
 - **At CHW**, "Allow Natural Death" (AND) orders in conjunction with primary team or
 - **At SCH**, Resuscitation Plan-Paediatric/Adult
 - Ambulance Form or letter for the family describing child's status and plan if ambulance is called.
- Ongoing provision of care when the child is discharged from hospital may include:
 - planning for monitoring and managing symptoms
 - identifying community groups/support
 - establishing and supporting, where possible, the hopes and wishes of the child and family
 - actively promoting ongoing contact with the primary team
 - flagging in Emergency Department, where appropriate
 - identifying spiritual or cultural requirements e.g. transporting a body home

6.4 Nutritional Needs

Children are encouraged to continue with normal nutrition as long as possible and a SCHN dietician may liaise with the family to maintain optimal nutrition. Loss of appetite associated with the dying process remains a major source of distress for families and consideration is given to this when discussing options for nutritional support of the child.

SPPC Services support continuation of nasogastric/PEG feeds. A PEG tube procedure will sometimes be carried out to provide nutrition during the palliative process. If further support is needed in this area contact:

- **At CHW:** Stomal Therapist (page 6154)
- **At SCH:**
 - *For Peg Feeds:* CNC Surgery and Wound Care (page 43164)
 - *For NGT:* CNC Gastroenterology (page 42568) or CNS Gastroenterology (page 10619)

6.5 Psychosocial Family Support

The SPPC clinicians will ask families about their existing support networks. A social worker will be available for the family either through the primary team or SPPC service. Psychological support can be accessed through the Psychology Department (SCH), or Department of Psychological Medicine (CHW) or the SPPC Service. Referrals to the SPPC Clinical Psychologist are through the SPPC clinicians. If families request or require further support the SPPC Service will make every effort to connect them to an appropriate provider. In most circumstances, a psychosocial assessment will be completed with families caring for a child with a life limiting illness.

6.6 Spiritual Care

The SPPC clinicians will explore the role of spirituality and religious and/or spiritual care networks with each family. If the family has religious connections they will often have established connections to these groups but the SPPC Service or clinicians involved can help liaise with these groups if required. Spiritual support groups can, in some cases, have a major role in the family's decision-making process and this should be discovered and if necessary a meeting with them arranged.

6.7 Allied Health

Allied Health members liaise with primary teams and therapists who may already be involved with the child and family to facilitate continuity of care and provide appropriate support. Referrals to speech therapy, dietetics and orthotics may also be required and this would be done in consultation with the primary team. A referral to occupational therapy may include a home assessment before discharge, and an assessment of the need for equipment, pressure care, home modifications and ongoing follow up needs.

- **At CHW:** Families are offered physiotherapy and occupational therapy on referral to SPPC if they do not already have access through their primary team. Speech pathology, dietetics are usually offered by the primary team.
- **At SCH:** Physiotherapy, occupational therapy, child life therapy, social work and psychology are part of the SPPC multidisciplinary service at SCH and are available to consult and provide services to children referred to the team.

6.8 Short term Palliative Care/End of Life Care

The role of the SPPC Service in end of life care will depend on the length of involvement with child and family. This may range from 'fast tracking' ward admission (to a ward known to the family) to avoid unnecessary distress through to advice / providing symptom management in a terminal care phase.

6.9 Medical Record Keeping

All treatments and interactions with the child and family should be documented in the child's medical record or PowerChart (CHW) or PCS (SCH).

7 Medications

7.1 Dosing Information

For information relating to doses, refer to:

- **At CHW:** [CHW Drug Dosage Guidelines](#) on the intranet
- **At SCH:** Refer to [Australian Medicines Handbook –Children's Dosing](#) Companion on the Clinical Information Access Portal (CIAP) For specific information on medications for symptom management see [Section 8](#).

7.2 Subcutaneous/IV Medications

When administration of medications by the oral route is not possible, it is necessary to change the route of administration to maintain effective symptom control. Circumstances requiring change to alternative routes include:

- swallowing difficulties
- inability to tolerate oral medications e.g. nausea, vomiting
- rapid dose titration
- intestinal obstruction
- comatose patients or those with decreased level of consciousness, due to disease progression or sedation

- terminal stage of illness – during the final 48 hours of life many patients are unable to continue oral medications.

Children often have Central Venous Access Devices (CVAD) (e.g. infusaport or central venous catheters) during their period of active treatment. Consideration should be given to insertion of a CVAD for pain and symptom management in children who do not already have a CVAD on an individual basis. The subcutaneous route is an alternative which removes the need for a CVAD.

8 Symptom Management

The adequate, proficient and timely management of symptoms is of critical importance. Not only is it important from a humanitarian viewpoint, but also it is apparent that the memory of unrelieved symptoms in dying children may be retained in the memory of parents many years after their child has died². It will be impossible for children and their families to negotiate the domains of psychological and spiritual care if physical symptomatology has not been adequately treated.

Medications should be reviewed regularly to ensure that unnecessary treatments are ceased as they may add extra burden to care, and contribute to other symptoms such as nausea and lethargy.

8.1 Pain

Pain that cannot be relieved using conventional treatment is intractable. Intractable pain that does not respond to therapies beyond conventional practice is refractory. The relief of refractory pain may require a therapy that compromises consciousness. The modalities of pain control for the management of intractable pain in paediatric patients include opioid dose titration, adjuvant analgesics, regional anaesthesia, and sedation. Non-pharmacologic methods of pain control have a secondary role in the setting of intractable pain.

When assessing pain, staff should use recognised pain assessment tools. For information about pain assessment tools see:

- **At CHW:** [Pain Management - CHW Practice Guideline \(Section 1.6\)](#).
- **At SCH:** [Patient Controlled Analgesia \(PCA\) – SCH](#)

Where possible, the oral route of administration is used. Regular doses of analgesia should be given by the clock for patients who have constant pain (e.g. bd every 12 hours, q 4 hr is every 4 hours) irrespective of whether the patient has pain. PRN or breakthrough dosing is to be used on an “as needed” basis for the management of incident and breakthrough pain.

8.1.1 Oral Analgesia

For mild pain, paracetamol or a non-steroidal anti-inflammatory drug (NSAID) can be used. Ibuprofen is often the NSAID of choice in children. Caution should be exercised when

prescribing paracetamol to children with liver dysfunction or for extended periods of time. Care should also be exercised when prescribing NSAIDs to children with renal impairment, dehydration, poor oral intake, heart failure, severe asthma and peptic ulceration. NSAIDs should also be avoided in children with cancer who are thrombocytopenic.

For moderate to severe pain, an opioid analgesic is used. Morphine mixture or oxycodone are the first line agents. Oxycodone also has the advantage of being available as tablets (Endone[®]) or Capsules (Oxynorm[®]). The medication can be given on an as required basis or regularly. The dosing interval is generally 4 – 6 hours. However if a child has persistent severe pain the dosing frequency can be increased to 1 – 2 hourly.

If a child is requiring a short acting opioid regularly and their analgesic requirements have stabilised they can be converted to a long acting preparation. Oxycodone preparations (Oxycontin[®]) are only available in tablet form, while morphine preparations (MS Contin[®]) are available as both tablets and dissolvable sachets. The total daily dose of short acting opioid is halved to give the morning and evening dose of a long acting preparation. In addition to the long acting dose a break through dose of a short acting drug can still be given every 1 – 2 hours for breakthrough or incidental pain. This dose is generally 1/6 to 1/10 of the total daily dose of opioid.

Other opioid preparations are available at the hospital including hydromorphone and fentanyl lozenges. Methadone is another agent which can be particularly effective when other agents have failed. Consultation with the SPPC Service should occur before these are prescribed by treating teams.

Refer to Table 1 for opioid preparations at CHW and SCH.

Table 1 - Opioid Preparations available at SCHN

Drug	Release	Form	Dose
Hydromorphone	Immediate	Liquid	1 mg/mL (Dilaudid®)
	Immediate	Tablets	2, 4, 8 mg (Dilaudid®)
	Controlled	Tablets	4 mg, 8 mg, 16 mg (Jurnista®)
		Injection	2 mg/mL, 10 mg/mL, 50 mg/5 mL (Dilaudid – HP®)
Methadone	Immediate	Liquid	5 mg/mL (Aspen methadone syrup®)
	Immediate	Tablet	10 mg (Physeptone®) ^a
		Injection	10 mg/mL (Physeptone®)
Morphine	Immediate	Liquid	1 mg/mL, 2 mg/mL, 5 mg/mL and 10 mg/mL (Ordine®)
	Immediate	Tablets	10 mg (Sevredol®) ^a
	Controlled	Granules	20 and 30 mg (MS Contin Sachets®)
	Controlled	Tablets	5, 10, 30, and 100 mg, 200 mg (MS Contin, Morphine sulphate Apotex)
		Injection	5 mg/mL, 10 mg/mL, 30 mg/mL, 120 mg/1.5 mL, 400 mg/5 mL (DBL)
Oxycodone	Immediate	Liquid	1 mg/mL (Oxynorm®)
	Immediate	Tablets	5 mg (Endone®) ^a
	Immediate	Capsules	10mg (Oxynorm®)
	Controlled	Tablets	5 mg (Oxycodone Sandoz®), 10, 15, 20 and 40 mg, 80 mg tablets (Oxycontin®)
Oxycodone/naloxone	Controlled	Tablets	5/2.5 mg 10/5 mg 20/10 mg and 40mg/20mg (Targin®) ^b
Tramadol	Immediate	Capsule	50 mg (APO Tramadol®)
	Controlled	Tablet	50, 100 mg (Tramal®, Tramedo®)
	Immediate	Oral Drop	100 mg/mL (Tramal®)
		Injection	100 mg/2 mL (Tramal®)

^a Tablets are scored

^b Prescribed according to oxycodone component

NB: Please be aware- medication brands can change. Please contact the department of pharmacy to enquire about the availability of these or other products.

Consideration to using adjuvant agents should also be given particularly when there is evidence of neuropathic pain. Agents that may be considered include amitriptyline, pregabalin and gabapentin.

8.1.2 Intravenous/Subcutaneous Analgesia

Opioids

Children will often require a background infusion to provide a consistent dose of drug during the day and night. In addition to the background infusion, additional doses for “breakthrough” and “incident” pain (e.g. pain on moving and coughing) need to be available. Where possible, patient controlled analgesia (PCA) is used. This refers to an infusion device, which can be

activated by the patient to self-administer a set bolus of the drug. In younger children, nurses will activate the infusion device. The PCA allows some control over the wide and often unexpected analgesic requirements of individual children by allowing for additional analgesia as required.

The daily dose of parenteral morphine for children who are already on morphine is 1/3 of their total daily dose of oral morphine. Breakthrough doses of opioid may be calculated as approximately 5% to 10% of the total daily opioid requirement. The PCA device must be programmed to deliver an opioid dose at a predetermined frequency, with a maximum total dose over a set time period. Post-operative data suggest that 7 year old children of normal intelligence can use PCA effectively to provide analgesia².

Guidelines for the initial prescription of opioids can be found:

- **At CHW:** [Pain Management - CHW Practice Guideline](#) (see also the Pain Management [shortcut table](#)).
- **At SCH:** [Opioid Intravenous Infusions](#)

8.1.3 Opioid Dose Escalation

If pain cannot be controlled by the opioid loading technique (above), then the subsequent opioid dose escalation may be calculated as follows:

- If greater than approximately six rescue doses of opioid are required in a 24 hour period, then the hourly average of this total daily rescue opioid should be added to the baseline opioid infusion. An alternative would be to increase the baseline infusion by 50%³.
- Rescue doses are kept as a proportion of the baseline opioid infusion rate and are re-calculated as between 50% and 200% of the hourly basal infusion rate³.

8.1.4 Opioid Switching (Fentanyl, Hydromorphone)

The usual indications for switching to an alternative opioid are dose-limiting opioid toxicity, insufficient analgesia or intolerable side effects (e.g. itch, nausea, neuro-toxicity). In these cases, an alternative opioid can be trialled. Options include fentanyl, hydromorphone and sometimes methadone. A switch from one opioid to another is often accompanied by change in the balance between analgesia and side-effects⁴.

The table below assists with conversion of morphine to fentanyl and hydromorphone. Both background and bolus doses should be taken into account when switching opioids. Switching to methadone is more complex and should be discussed with the SPPC Service.

In order to limit the risk of error, prescriptions for hydromorphone must include the trade name of the preparation intended for use.

Table 2 - Parenteral Opioid Drug Conversions

Drug	Morphine	Fentanyl	Hydromorphone
Relative Potency	1	40	5-7
Example Dose Comparisons	4 mg	100 micrograms or 0.1 mg	570 micrograms

Please refer to: [CHW Pain Management Practice Guideline-Section 5.5](#)

Opioid comparative information

[17 8 15 Inpatient policy review ES MM PJ.docx](#) (Adapted from The Australian Medicine Handbook, July 2015, Available at: <https://amhonline.amh.net.au.acs.hcn.com.au/chapters/chap-03/tables/comp-inf-opioid.tb>) (See Appendix)

8.1.5 Transdermal Analgesia

The transdermal route should also be considered in the case of fentanyl. A child would need to be receiving approximately 15 mg of parenteral morphine (or 45 mg of oral Morphine) a day before consideration could be given to starting a 12 micrograms/hour fentanyl patch. Analgesic requirements should also be stabilised at the time of commencing a patch. Full effect of the patch takes 12 – 18 hrs after commencement of the first patch. Assistance with reducing previous opioid can be obtained from the SPPC Service.

8.1.6 A Paediatric Pain Crisis

A pain crisis in a child is an emergency. A specific diagnosis must be made, as therapies directed at the primary cause may be more effective in the longer term. The management of intractable pain requires the clinician to be at the child's bedside to titrate incremental intravenous doses every 10-15 minutes until effective analgesia has been achieved. The analgesic effects of opioids increase in a log-linear function, with incremental opioid dosing required until either analgesia is achieved or somnolence occurs³. The total amount of opioid administered to achieve this reduction in pain intensity is considered the opioid loading dose. A continuous infusion of opioid may need to be commenced to maintain this level of analgesia, and the infusion rate is often based on the opioid administered as a loading dose⁵. An alternative to a continuous infusion of opioid is intermittent parenteral opioid, especially in the setting of an unpredictable pain syndrome.

8.1.7 Sedation as a Therapeutic Modality for Intractable Pain

The use of sedation in the setting of refractory pain generally assumes that therapies beyond the conventional have been utilised and that there is no acceptable means of providing analgesia without compromising consciousness. This trade-off between sedation and inadequate pain relief requires the consideration of the wishes of the child and his or her family. A variety of drugs have been used in this setting, including barbiturates, benzodiazepines and phenothiazines⁶.

The ethical issues surrounding prolonged sedation in paediatrics, including the principle of double effect have been reviewed previously⁵⁻⁷. The continuation of high-dose opioid infusions in these circumstances is recommended to avoid situations in which a patient may have unrelieved pain but inadequate clarity to express pain perception.

8.2 Dyspnoea

Dyspnoea, which has been defined as “an uncomfortable awareness of breathing”⁸, is more common and often more severe in the last few weeks before death. It is often distressing to the patient and difficult for the family to watch. Additional support may be needed.

Terminal dyspnoea may be due to a variety, and perhaps combination, of causes. These include pulmonary metastases, intrinsic lung disease or infection, cardiac failure, acidosis,

muscle weakness etc. Diagnosis is important as this may influence choice of therapies. Non-invasive ventilation may be a viable choice for symptom management of dyspnoea related to muscle weakness, for example, and bronchospasm could potentially be reversed with bronchodilators.

The goal of palliative therapies for dyspnoea is to improve the patient's subjective sensation. Systemic opioid therapy^{8,9} and cognitive-behavioural strategies¹⁰ and simple measures such as use of a fan¹¹ have been shown to be of benefit to patients with dyspnoea. As anxiety is often a component of dyspnoea, judicious prescription of a benzodiazepine may be warranted.

8.3 Constipation

Constipation is a relatively common symptom in children receiving palliative care. The aetiology of constipation is often multi-factorial and may include reduced physical activity, mechanical obstruction, metabolic derangement, poor diet and low fluid intake, bowel atony due to opioids. Bowel obstruction and faecal impaction, though unusual must be excluded and treated urgently in any child presenting with constipation. Constipation may also cause faecal overflow, urinary retention and pain.

Management of constipation may include:

- Dietary changes
- Appropriate hydration
- Increased mobility where feasible
- Introduction or review of laxatives
- Appropriate facilitation of activities of daily living and toileting facilities

Laxatives

Movicol[®] is the most effective laxative (Macrogol 3350 with electrolytes). Children will often be started on Movicol - half[®] formulations..

Other options for managing constipation include paraffin oil, (Parachoc[®] is chocolate flavoured), lactulose and Coloxyl with senna[®]. Coloxyl with senna[®] can be effective in adolescents who may not want to take syrup. Microlax[®] enemas or glycerine suppositories can be considered in children unable to take medications by the oral route (caution should be exercised in children with low platelets or neutropaenia).

8.4 Seizures

Seizures in palliative care patients may be either recent in onset or part of a long-standing underlying seizure disorder. If recent in onset, it can be upsetting to patients and families. Seizures may be due to many possible causes (e.g. cerebral metastases, infection, metabolic disorder, hypoxia etc.) which must be excluded as treatment directed at the primary causes may be appropriate whilst anti-convulsant therapy is implemented. Where they are part of a long-standing disorder, worsening seizure control may indicate either disease progression or factors related to anti-convulsant dose, class, or administration which should be reviewed.

Seizure Management

Buccal/Intranasal midazolam is the first line agent for breakthrough seizure management where seizures are not controlled by prescribed anticonvulsants. It has been shown to be at least as effective as rectal diazepam in the acute treatment of seizures¹².

- buccal/intranasal midazolam: 0.2–0.3 mg/kg (maximum 10 mg) as a single dose only, maybe repeated once after 5 – 10 minutes.
- http://chw.schn.health.nsw.gov.au/o/documents/policies/drug_protocol/2013-7024.pdf

Maintenance drugs are usually required for seizure management (e.g. phenytoin, phenobarbitone, valproate, clobazam). If frequent buccal/intranasal doses of midazolam are required, a midazolam bolus can be administered intravenously or subcutaneously. Consideration should be given to commencing a midazolam infusion at this time.

- **At CHW:** see [Midazolam Infusion for Management of Seizures in CT Ward - CHW Practice Guideline](#).

Initial treatment of status epilepticus in children typically consists of either diazepam or midazolam, immediately followed by phenytoin or phenobarbitone¹³.

The Neurological Service can advise on seizure management (contact On Call Neurologist via hospital switch 9382 1111 (SCH) or 9845 0000 (CHW)).

8.5 Nausea and Vomiting

Nausea and vomiting are common in children receiving palliative care. They occur when the vomiting centre in the brain is activated by any of the following:

- cerebral cortex (e.g. anxiety)
- vestibular apparatus
- chemoreceptor trigger zone (CTZ)
- vagus nerve
- direct action on the vomiting centre

Determining the aetiology will help direct therapy as the list of potential causes is great and therapies differ, depending on the putative mechanism.

Table 3 – Nausea and Vomiting Causes and Treatments

Cause	Putative Mechanism ¹⁴	Treatment
Gastrointestinal causes: Poor mouth care Gastric irritation Intestinal obstruction Constipation Hepatic distension	Cerebral cortex, vagus Vagus Vagus Vagus Vagus	Regular mouth care Exclude drug related causes, consider prescription of H1 antagonists May require surgical opinion Laxatives (see below) Depends on aetiology (e.g. frusemide for cardiac failure, dexamethasone for tumour related causes)
Metabolic causes: Renal failure Hypercalcaemia	Chemoreceptor trigger zone (CTZ) CTZ	Consider anti-emetics if more invasive therapies not appropriate If appropriate, consider hydration, diuretic (osteoclast inhibitors may also be appropriate)
CNS causes: Raised intracranial pressure Vestibulitis	Vomiting centre Vestibular apparatus	Dexamethasone Antihistamine
Treatment related causes: Medications (chemotherapy, opioids etc)	Chemoreceptor trigger zone Vagus	Consider an opioid switch for dose limiting side-effects
Psychological trigger: Anxiety Emotional distress	Cerebral cortex Cerebral cortex	Consider cognitive –behavioural therapy alongside medication
Other causes: Pain Infection Migraine headache Situational triggers (unpalatable food etc)	Vagus Chemoreceptor trigger zone, Vomiting centre Vagus Cerebral cortex	Treat the primary cause Treat the primary cause Anti-migraine therapies Alter situation

8.5.1 Anti-emetics

Common anti-emetics that are used include ondansetron (wafer, tablet and syrup), metoclopramide (syrup and tablets) and cyclizine. A child should be monitored for extra-pyramidal side effects when commenced on metoclopramide. These effects can be reversed with Benztropine.

Cyclizine(Nausicalm[®] tablets, non-SAS) is an effective anti-emetic particularly in children with central nervous system pathology.

Other options for anti-emetics include haloperidol, levomepromazine and lorazepam. Consultation with the Pain and Palliative Care Service is advised before commencing these medications.

A TGA Special Access Scheme(SAS) form, either Category A or Category B, needs to be completed to access medications that are unapproved by the TGA (e.g. levomepromazine).

Ondansetron, metoclopramide, cyclizine, haloperidol and levomepromazine can all be administered by the subcutaneous or intravenous route. They can be given as a bolus or as part of an infusion. **Please check dosages if you are unfamiliar with these drugs.**

Compatibility with other drugs in the infusion should be checked. Access to ondansetron varies between hospitals – if you have any queries, please contact the Specialist Palliative Care team.

8.6 Secretions

Secretions can be a significant symptom in some children which may or may not require intervention. Individual assessment is required and management may include positioning, suctioning and possibly anticholinergics. In the terminal phase, noisy secretions should be discussed with the family because of the potential for family distress. Hyoscine hydrobromide and glycopyrrolate are the most commonly used anticholinergics¹⁵.

Hyoscine hydrobromide or glycopyrrolate are initially given as bolus doses but can also be administered intravenously. Dosing is also possible by oral and transdermal routes. For information on dosing:

- **At CHW:** see [CHW Drug Dosage Guidelines](#).
- **At SCH:** see [Australian Medicines Handbook –Children's Dosing](#) Companion

8.7 Bleeding

Families and carers of children dying from either haematological malignancy or liver failure may fear external bleeding. This mode of death in childhood is rare. Where significant bleeding is a potential issue, an appropriate management plan needs to be in place e.g. crisis medication and use of dark towels.

8.8 Mouth Care

Routine mouth care promotes patient comfort and ability to eat and drink, prevents halitosis and helps to identify problems such as dry mouth, candidiasis and ulceration¹⁴. Lip emollients and mouthwashes are important therapies for mouth care. The sensation of a dry mouth may be due to local (e.g. mouth breathing, candidiasis, radiotherapy to salivary glands etc.) and systemic causes (e.g. dehydration, anticholinergic drugs, uraemia etc.) and is often distressing.

8.9 Hydration

The issue of hydration in dying patients may be a complex issue. As with all therapies, the benefits and deficits of any intervention must be discussed with the patient and family before any therapeutic intervention is implemented. Small but frequent volumes of fluid to maintain insensible losses may be appropriate via the oral route. However, this may be impossible in some instances unless other routes of administration are considered.

8.10 Pressure Area and Skin Care

Appropriate maintenance of skin integrity includes education regarding the monitoring of skin integrity and the provision of a skin care regime. This may include assessment for the use of equipment e.g. pressure care mattress and hoists.

- See [Pressure Injury Preventions and Management Policy](#)

8.11 Terminal Delirium

Delirium during the final phase of dying is one of the most distressing symptoms for caregivers to watch, especially if the delirium is manifested as agitation. The aetiology of delirium in the setting of an actively dying patient is usually multifactorial with a physical rather than psychological basis (e.g. hypoxia, metabolic derangement, central nervous system disease, infection, fever etc.). As terminal delirium cannot be predicted, a therapeutic plan for its management should be considered in every dying child.

The usual therapies consist of haloperidol for delirium per se with consideration of adding a benzodiazepine if there is agitation as well. Use of non-pharmacological approaches and optimising pain relief is often beneficial in this setting. These may include imagery, relaxation, massage or simply being with the child allowing them to talk about their feelings.

8.12 Anxiety

Children often feel grief, depression and a sense of lost hope at their time of death. Allowing the child to talk openly about their feelings with people they trust can help alleviate anxiety and misconceptions. Additionally, fears that the child may have include pain and being alone. Reassurance and including them in the planning process of pain management may assist them to feel less powerless and helpless and more in control¹⁶.

Anxiety, particularly at night, can be a significant symptom for children receiving palliative care. An attempt should always be made to address the underlying cause and use non-pharmacological approaches to managing this symptom. Non pharmacological approaches could include relaxation techniques, distraction, massage, music and meditation.

Diazepam or Clonazepam can be used. Clonazepam has the advantage of a longer half-life and can be administered sublingually in droplet form. Midazolam can also be administered via the buccal/ intranasal route for anxiety, or agitation.

These medications can also be effective in relieving dyspnoea in part related to the anxiolytic effect.

Midazolam can also be used to treat agitation. Other alternatives for treating agitation include promethazine, haloperidol and levomepromazine (See [Drug Dosage Guidelines](#) at CHW).

8.13 Insomnia

The aetiology of insomnia is multi-factorial and is often a combination of physical, psychological and perhaps environmental factors. When depression is a factor, consideration should be given to psychotherapy and pharmacologic treatment. Lifestyle changes, including improved sleep hygiene and exercise may be helpful to improved sleep. Low doses of Amitriptyline or Melatonin are often helpful pharmacologic agents for the management of insomnia in terminally ill children. Amitriptyline may be helpful particularly if pain is a symptom management issue.

Note: Melatonin is available as 3mg lozenges (immediate release) which are SAS and 2mg SR (slow release) tablets which are not SAS.

Melatonin is non-formulary at SCH and requires completion of an [Individual Patient Use application](#).

8.14 Fatigue

Fatigue is a common symptom of children with cancer¹⁷⁻²⁰ and one that is often highly distressing. The aetiology of fatigue in children may be due to a combination of factors including: anaemia, poor nutrition, insomnia, metabolic derangement, the increased work of breathing in children with dyspnoea, side-effects of medication, and psychological factors.

In the assessment of fatigue in a child, and the matrix of its potential causes, it is important to establish if this symptom is distressing to the child and/or his family. If so, the potential remediable causes should be considered. Therapies directed at the primary cause should be instituted only if these therapies are not of substantial burden to the patient and/or his family. There are limited paediatric data on the use of stimulant medication for the treatment of opioid induced somnolence^{4, 21-23}. In children it has become more common practice to switch opioids (see above) for somnolence as a dose-limiting side-effect of opioid therapy.

9 Discharge from Hospital to Home

It is recommended that a referral is made as early as possible to SPPC Services to assist wards with discharge planning and ensure links are made to appropriate community services.

9.1 General Practitioner (GP)

It is imperative that the family is linked in to a GP before, or as soon as possible after, discharge. In some instances, a paediatrician will provide the support usually provided by a GP, in which case, the following also applies to the Paediatrician. In the absence of a known GP, community nursing will usually help with locating a GP. The GP must be willing to do home visits.

- GP involvement is necessary for:
 - continuity of medical follow up close to home
 - managing intercurrent problems
 - family support
 - signing of a death certificate
- Refer to:
 - The Death of a Child Procedure (Coroners and Non-Coronial)
 - **or** NSW Health Policy [PD2010_054 Coroners Cases and the Coroners Act 2009](#)
- The GP must be provided with a comprehensive home care plan including:
 - child's condition
 - current medications
 - estimated prognosis
 - end of life symptom management plan if appropriate

- contact details of all clinicians involved
- **at CHW**, a copy of Ambulance Form (from SPPC) and/or the NSW Resuscitation Plan-Paediatric/ Adult **at SCH**, NSW Resuscitation Plan-Paediatric/Adult, if appropriate (from SPPC)

9.2 Community Nursing/Community Palliative Care Referral

Dependent on need, children receiving palliative care who are discharged home may be referred to community nursing. As the child approaches the terminal phase, the community nursing team and community palliative care team may be involved. The SCHN palliative care clinicians will liaise regularly with community nursing to offer support and provide an integrated service to the family. The SPPC, or primary team CNC, will refer to community nursing and an initial joint visit will be made by all parties to the family home where possible.

Role of these Teams:

- assist with symptom management in liaison with SPPC
- provide equipment on occasions
- provide support in form of phone calls and visitations
- provide after-hours/weekend visiting and trouble shooting
- act as a link to other community services e.g. palliative care, schools, counsellors

When possible attend case meetings before discharge. For more information, see [SCHN Palliative Care at Home Practice Guideline](#).

9.3 Care Planning

When a patient is being discharged from hospital, it is essential for the relevant hospital teams to ensure there is an ongoing care plan to support the child and family at home. Care planning aims to establish clear goals and lines of communication between the multiple health teams providing care. This care plan is usually in the form of a discharge summary incorporating the child's ongoing management. The following relevant details should be included: Contact Details of all treating health care teams

- Symptom Management
- Equipment supply
- Nutritional Needs
- Psychosocial Family Support
- Spiritual/religious Support

9.4 Contact details of staff

A contact list of clinicians involved in the child's care should be included in the home management plan. This should include name, designation, phone number and when they can be contacted. There must be clear directions about who to contact in an emergency.

9.5 Contact by hospital staff

Support given by staff will vary from family to family and will also be dependent on the child's condition. Information must be given to the family advising them who will be contacting them, who will be visiting their home and when that will be. All hospital teams involved in the care of the child need to co-ordinate family contacts so that families are not contacted inappropriately.

9.6 Transport from Hospital to Home

If a decision is made to transport the patient from hospital to home, one of the following modes of transport will be selected:

9.6.1 Self-Transportation

This mode and time of transport is usually arranged by the family and an assessment needs to be done to ensure a safe environment for transport home. Also ensure that the family have the necessary equipment/devices for transfer.

9.6.2 Hospital Transport

If hospital transport is required to the home, the transport department must be informed and Patient Transport Request online form completed by 1300 hours on the day of transport (available from Monday to Friday). Specify the type of transportation needed (i.e. car, station wagon, ambulance). All transfers require an escort who may be a parent or health care professional.

For information on **transport safety issues** see [SCHN Transporting Children Under 16 years Including Exemptions for Child Restraints and Booster Seats Policy & Procedure](#).

- For **transfers to [Bear Cottage](#)** (children's hospice): Call direct to discuss options.
- For information on transferring patients, see [SCHN Transfer and Transport of Patients within SCHN Hospitals Procedure](#)
- For **transfers from CHW**: See [CHW Intranet - Transport](#) or see CHW online booking form [Patient Transport Request Form](#)
- For **transfers from SCH**: See SCH online booking form [Patient Transport Booking Request Form](#).

9.6.3 Emergency Transport

Emergency ambulance will be organised via emergency services following 000 procedures. All children receiving palliative care can have an Ambulance Form, which documents the end of life care choices. This outlines the support to be provided by the paramedics, and may include information about transport to hospital.

9.6.4 Other Transport Options

- Community Ambulance can be organised by phoning them directly on 131 233 (Note: emergency situations will be given priority). Generally, transport times are nominated as morning or afternoon/evening blocks. Check if the family have information regarding costs of transfer by ambulance.
- 'Angel Flight Australia is a charity organisation which co-ordinates non-emergency flights for eligible rural families, operated by volunteer pilots.'

- CareFlight (CHW) or Wing Away (SCH) is usually arranged by the Primary Team
- NETS is arranged by the child's physician

9.7 Equipment Supply

Supply of equipment for children receiving palliative care follows the same process as any child being discharged from hospital. If the child is approaching end of life, occupational therapy/physiotherapy should be consulted as soon as possible so that support can be provided as early as possible.

See [Equipment Hire from the Equipment Loan Pools Procedure](#)

10 Special Issues

10.1 Adolescent and Young Adult Issues

Palliative Care of an adolescent or young adult follows the same process as any other palliative patient. Issues for particular consideration include:

- Consent
- Transition to adult services
- Need for increased independence in decision making
- Fertility and sexual health issues

10.1.1 Consent

- Refer to [Consent to Medical Treatment - Patient Information Policy](#) [from NSW MoH].

10.1.2 Giving of Information

Before giving information to an adolescent/young adult, the maintenance of family integrity should be considered. It is prudent to attain family agreement regarding disclosure of information that is consistent with that particular family's usual way of communication and will not cause the adolescent/young adult or care-givers undue distress. However, a child over 14 years of age has the legal right to be given information regarding their condition. This needs to be considered if the child is asking for information, even if it is in conflict with the wishes of the parents/caregivers.

10.2 Specific Cultural Issues

The complex interweaving of an individual's personality, family, society, culture and religion makes generalisations about culturally sensitive care inappropriate. The health care professional should ask parents about their cultural and other beliefs and respond to them accordingly.

10.2.1 Patients who identify as Aboriginal or Torres Strait Islander

The needs of patients and their families who identify as Aboriginal or Torres Strait Islander need to be carefully considered.

The SPPC Service should recognise the diversity of beliefs and culture around death and dying for patients and their families who identify as Aboriginal or Torres Strait Islanders and should respond to their needs accordingly. For further advice:

At CHW: Please contact the Aboriginal Health Management Advisor [ext. 53021] or the Aboriginal Health Education Officer [ext. 53630].

At SCH: 'Please contact Social Work Department (9382 1021) or after-hours via switch, who will liaise with relevant cultural support if available'.

10.2.2 Families for whom English is not their first language

If there is any doubt about the family's ability to communicate in or understand English, an interpreter should be engaged.

At CHW: Please contact Health Care Interpreter Service (HCIS) 9912 3800 or Telephone Interpreter Service (TIS) 131450

At SCH: Please contact Health Care Interpreter Service (HCIS) 9515 0030 or Telephone Interpreter Service (TIS) 131 150.

11 Palliative and Respite Care at Bear Cottage

Bear Cottage provides palliative respite and end of life care for children with life limiting illnesses and their families in a friendly home-like environment. The care team comprises nursing and medical staff, play, music and art therapists and social workers.

Criteria for admission to Bear Cottage: children with a life limiting illness from which death is expected before the adult years.

Bear Cottage provides regular booked respite, emergency respite; step down from hospital to home, symptom management, end of life care and bereavement care.

Priority for Admission

- Children and young people requiring end of life care where Bear Cottage is the preferred location of care
- Emergency admission for symptom management
- Emergency respite admission
- Booked respite admissions

Family Accommodation

Bear Cottage has capacity to accommodate the family as a whole. Parents and siblings are welcome to stay with their child in our home like environment. Care is family centred ensuring that each families individual needs are met.

11.1 Planned Respite Care

11.1.1 Referral Process

Referrals can be made to Bear Cottage by health care professionals, families or carers / friends in conjunction with the parents' approval.

If the referral is made by a health care professional it can only be treated as a preliminary inquiry until the parents have been spoken to and given consent for the referral.

A Bear Cottage Child/Family Information Form (Medical Officer) form will need to be completed by the medical officer most involved in the child's care and a separate form will need to be completed by the family. These will need to be completed prior to a decision being made as to the child's eligibility. If there are any questions regarding the child's eligibility we strongly advise ringing Bear Cottage prior to giving the form to the family to fill complete. The Medical Officer and Child/Family Information Forms will be posted to either the person making the call or the parents. They are also available on the Intranet.

- See [Bear Cottage Child/Family Information Form](#) **OR** [Bear Cottage/Medical Referral Form](#)

For routine referrals no decision will be made prior to receiving the completed referral forms and relevant information. Once a decision is made the family and / or the referring person will be contacted to discuss the outcome and potential booking if the child is eligible. For each new admission to Bear Cottage a Paediatric National Inpatient Medication Chart (NIMC) must be completed.

11.1.2 Bookings

Bookings for planned respite are made with the Nursing Unit Manager. Three weeks prior to the admission date the family will be sent confirmation of dates, a medical update form and medication charts to be completed by their medical officer. This paper work can be returned by mail to Bear Cottage or brought in with the child on admission. The admission can only proceed if the relevant paperwork is completed.

Emergency Admission to Bear Cottage

Bear Cottage provides emergency palliative and respite care for children with life limiting illnesses and families. Emergency care includes:

- end-of-life care
- admission for symptom control
- emergency respite admissions

Referrals for emergency admission can be taken by the Nursing Unit Manager during business hours or the Registered Nurse in charge of the shift after hours. Appropriate paperwork is to be faxed/ emailed to the relevant medical officer for completion and the Bear Cottage GP is to be notified of the pending admission once the decision to accept is made.

11.2 Duration of Admission

Duration of admission for children needing end of life care will be open-ended.

Up to four weeks of respite, dependant on availability will be offered to families per year dependant on the family's needs. Only one week can be booked in NSW school holiday periods and only every second school holidays. Respite admissions are reliant on demand and maybe cancelled in the event of an emergency admission. Management of Emergencies

11.3 Presentation to the Emergency Department (ED)

A child receiving palliative care who presents to ED should be assessed and treated the same as usual ED protocol, even during end of life care. In order to determine cause of symptoms, a thorough history and physical examination should be undertaken. Laboratory investigations and medical imaging should be undertaken, unless the child's physician (or PCS) in consultation with the family has requested otherwise.

These children should have been previously "flagged" for ED staff to identify that they are receiving palliative care. Goals of care should be checked with the parent or carer to ensure they are still current.

- **At CHW** any Allow Natural Death (AND) Form will be located in PowerChart under the Acute Management Plan menu. This will need to be reviewed and updated if necessary by the attending ED physician.
- **At SCH**, There will be an eMR Clinical Alert in place if a child has a Resuscitation Plan- Paediatric/Adult. A scanned copy of the Resuscitation Plan-Paediatric/Adult can be accessed from Powerchart. Please see Quickstart instructions to access scanned records
(http://sch.sesahs.nsw.gov.au/departments/hiu/resources/QuickStart_for_Scanned_Health_Records.pdf)

Children who are receiving palliative care at home may have many clinical issues which require intervention and necessitate presentation to the ED. Unanticipated problems require assessment and possible intervention. In an emergency situation, all relevant family members or significant people may not be present to discuss the management of these symptoms. This should be considered when making a decision regarding the implementation or withholding of potentially lifesaving measures.

Many measures taken to relieve suffering and improve a child's comfort, although resembling 'treatment' can primarily alleviate physical symptoms and psychological distress that the child and/or family may be experiencing.

Unanticipated problems may include sepsis, bleeding, uncontrolled pain, seizures, dyspnoea, uncontrolled vomiting and unconsciousness. See [Section 8](#).

11.4 End of Life Decision Making in ED

Where possible, documentation for end of life care planning should be filled out and families given ample opportunity for discussion. Pre-existing documentation should be provided to the ED. If there is no record on Powerchart of an Allow a Natural Death form [CHW] or Resuscitation Plan- Paediatric/ Adult [SCH], treatment will be given according to regular protocols

- **At CHW**, an Allow Natural Death Form (AND) is available on PowerChart for end of life discussions. This form will document the supportive care measures, which will be initiated and maintained whilst the child is in CHW care and provision is made for a 'standing order' when relevant. Some families, despite the knowledge that the child has a terminal illness, are unable to agree to an order to 'allow a natural death' for their child.
 - [CHW Allow a Natural Death By Limiting the Use of Life Sustaining Treatment Policy](#)
- **At SCH**, the Resuscitation Plan-Paediatric/Adult is available and should be ordered by each hospital ward ([Ordering these forms](#)). Please contact the paediatric palliative care service if further information is required when completing the Resuscitation Plan-Paediatric/Adult.
 - [Resuscitation Plans-End of Life Decisions Policy](#)
- For more information, see Section 13 (below)

11.5 Admission to Intensive Care Units (PICU, CICU or GCNC)

If a child receiving palliative care deteriorates while in SCHN, decisions to intubate/admit to CICU/PICU/GCNC will be made by the Resuscitation Team & CICU/PICU/GCNC consultant on-call in conjunction with the child's physician and family, unless AND order/Resuscitation Plan-Paediatric/Adult have been discussed and agreed upon.

12 End of Life

12.1 Care

End of life care is based on individual patient and family needs and the family can be supported at home, in hospital or at Bear Cottage.

Irregular and/or noisy breathing, prolonged periods of apnoea and colour change are common pathophysiologic accompaniments of dying over hours or even days. If parents/carers are forewarned about these manifestations of dying, the inevitable shock and fear associated with this process may be lessened.

See [Section 8](#) for Symptom Management.

12.2 Documentation

Where possible, documentation for end of life care planning should be filled out and families given ample opportunity for discussion.

Families may have already had discussions with their primary physician or SPPC team in terms of 'end of life decisions' and plans for how care will be managed in the event of an acute and/or life threatening event.

- **At CHW**, an Allow Natural Death Form (AND) is available on PowerChart for end of life discussions. A 'standing order' can be nominated by the carers for the duration of a single admission. See [CHW Allow a Natural Death By Limiting the Use of Life Sustaining Treatment Policy](#).
- **At SCH**, Resuscitation Plan- Paediatric/Adult can be ordered by each hospital ward (section 12.2).

For further information please see guideline below. These forms will document the supportive care measures which will be initiated and maintained whilst the child is in hospital.

Some families, despite the knowledge that the child has a terminal illness, are unable to agree to any limitation of resuscitation. These wishes should be respected. If there are no AND or Resuscitation Plan-Paediatric/Adult usual protocols for the care of the deteriorating child should apply.

13 Following the Death of a Child

This section should be read in conjunction with:

- **At CHW:** [Death of a Child \(Purple Folder\) Procedure](#)
- **At SCH:** [Death of a Child \(Non-coronial\) Procedure](#) or [Cultural and Religious Beliefs about Death and Care of the Body After Death](#)
- NSW Health Policy [PD2010_054 Coroners Cases and the Coroners Act 2009](#)

13.1 Information for parents

It is vital that the family are informed about procedures after their child dies. The following information must be covered:

13.1.1 Care of the Body

The SPPC Service or other staff should ensure that the family are offered the opportunity to discuss care of the body after death (special considerations for Coroners case- see 14.2) Discussion points may include:

- Washing and dressing the body
- Any cultural issues that staff need to be aware of
- Memoirs such as photos of their child, taking hand and footprints, taking a lock of their child's hair or recording their child's height and weight.
- Although a child's body is meant to be refrigerated within eight hours and buried or cremated within seven days, these rules are not rigidly enforced.

See [Burials - Exemptions - Public Health \(Disposal of Bodies\) Reg 2002 for Community and Religious Reasons](#).

13.1.2 Certifying Death

When a child dies at SCHN, appropriate documentation should be completed as per:

- **At CHW:** [Death of a Child \(Purple Folder\) Procedure](#)
- **At SCH:** [Death of a Child \(Non-coronial\) Procedure](#) or [Death of a Child \(Coroners Cases\) Procedure](#)
- or NSW Health Policy [PD2010_054 Coroners Cases and the Coroners Act 2009](#)

13.1.3 Transfer to home or private location (e.g. mosque) after death in hospital

If the family wish to take the body to a private location e.g. Mosque they must have documentation with them (Medical Certificate of Cause of Death).

In addition, **at SCH** it is recommended that staff provide a signed letter detailing the transport arrangements, and ensure this letter accompanies the child. A draft Transportation of Deceased Patient form is available online.

See also NSW Health PD2007_004 [Burials - Exemptions - Public Health \(Disposal of Bodies\) Reg 2002 for Community and Religious Reasons](#).

13.1.4 Funeral arrangements

The parents or their proxy should telephone a funeral director at a convenient time and inform them of the child's death and make arrangements for the child's body to be transferred to the funeral director or arrange for them to collect the child's body. The parents should also be informed that they can arrange to see their child's body again at the hospital or at the funeral directors before the funeral.

13.2 Notifying the Coroner - Children who have Department of Family and Community Service (FACS) Involvement

A medical practitioner should report the child's death to the Coroner if:

- At CHW: Please refer to [Death of a Child \(Purple Folder\) Procedure](#)
- At SCH: Please refer to [Coroners Cases Protocol](#)
- A report has been made to FACS about the child within 3 years immediately preceding the child's death, **or**
- A report has been made to FACS about any of the child's siblings within 3 years immediately preceding the child's death.

See NSW Health Policy Directive PD2010_054 [Coroners Cases and the Coroners Act 2009](#).

13.3 Care of the Child and Family After Death at Bear Cottage

Following the death of a child at Bear Cottage the GP on call will be notified and attend Bear Cottage.

- CHW is notified via the Chief Medical Officer by completing the "Death Notification" form on the CHW Intranet.
- SCH is notified directly by Bear Cottage staff. Nursing staff will also notify all relevant health care professionals during business hours.

Family and friends are able to spend as much time with their child up to 3 days after the death of a child. Staff will consider and accommodate the cultural needs of the family.

If a child dies elsewhere and the family wish to spend a few days with their child before burial, transfer to Bear Cottage could be considered, if an appropriate room is available that can accommodate the child and family.

14 Bereavement Follow Up

At the SCHN Bereavement support to family members and significant others has become recognised as an integral part of the provision of palliative care²⁴.

The following services may be available for bereavement support:

- Individual bereavement counselling sessions
- Adult parent support group as couples
- Fathers support group
- Mothers support group
- Sibling support groups
- Information in the form of literature or books
- Referral to outside bereavement agencies
- Phone call or card at time of first anniversary of child's death
- Memorial Days
- Social workers routinely undertake a risk assessment of all families to identify the possibility of complicated grief reactions.

For more information see [CHW Bereavement Support Practice Guideline](#).

15 Transition to Adult Services

Refer to:

- [SCHN Transitional Care Policy](#)

16 Organ Donation

Families expressing an interest in organ donation should be encouraged to discuss the process with their primary care team. Refer to relevant SCHN policies.

17 Post Mortem

Ideally options for post mortem should be discussed with the family prior to the child's death. If post mortem tissue sampling (skin, liver and muscle) is required for disease diagnosis and/or genetic counselling. These procedures must be performed at a hospital within two hours of death. The pathologist on call needs to be contacted to arrange these procedures.

18 Service Evaluation and Quality Improvement

The provision of palliative care by the SPPC Service may be evaluated by the following methods:

- Consumer satisfaction surveys – this may include surveying patients/family members, or members of the primary health care team
- Monitoring of complaints
- Collection, collation and analysis of Palliative Care Clinical Indicators
- Review of each death in relation to the Palliative Care Standards
- ACHS EQulP Accreditation
- National Standards Assessment Program (NSAP) for paediatric palliative care
- Quality Systems Assessment, NSW Ministry of Health

19 Incident and Complaints Management

19.1 Incidents

All clinical incidents at Westmead and Randwick campuses will be recorded in the Incident Information Management System (IIMS) and managed in accordance with [NSW Health Incident Management Policy Directive](#).

- **At CHW**, further information can be found at [Incident Management – CHW policy](#).

19.2 Complaints

Refer to the NSW Health Policy Directive [Patient Complaint Management Policy](#), where links to the NSW Health Complaint Management Guidelines is also available. In addition:

- **At CHW**, patient complaints are not recorded on IIMS and are managed in accordance with the [Patient Complaints Management – CHW Procedure](#).
- **At SCH**, see [Patient Complaint Handling Procedure](#).

20 References

1. World Health Organization, 2012, 11.7.2012, www.who.int/cancer/palliative/definition/en/
2. Berde CB, Lehn BM, Yee JD, et al. Patient controlled analgesia in children and adolescents: a randomized, prospective comparison with intramuscular morphine for post-operative analgesia. *Journal of Pediatrics* 1991; 118:460-466.
3. Cherny NI, Foley KM. Non-opioid and opioid analgesic pharmacotherapy of cancer pain. In: Cherny NI, Foley KM, editors. *Hematol Oncol Clin North Amer.* 1996: 79-102.
4. Galer BS, Coyle N, Pasternak GW, et al. Individual variability in the response to different opioids: report of five cases. *Pain* 1992; 49:87-91.
5. Truog RD, Berde CB, Mitchell C, Grier HE. Barbiturates in the care of the terminally ill. *New England Journal of Medicine* 1992; 327:1678-1682.
6. Kenny NP, Frager G. Refractory symptoms and terminal sedation in children: ethical issues and practical management. *J Palliat Care* 1996; 12:40-45.
7. Truog RD, Burns JP, Shurin SB, Emanuel EJ. Ethical considerations in pediatric oncology. In: Pizzo PA, Poplack DG, editors. *Principles and Practice of Pediatric Oncology.* Philadelphia: Lippincott Williams & Wilkins, 2002: 1411-1430.
8. Bruera E, MacEachern T, Ripamonti C, Hanson J. Subcutaneous morphine for dyspnea in cancer patients. *Annals of Internal Medicine* 1993; 119(9):906-907.
9. Boyd KJ, Kelly M. Oral morphine as symptomatic treatment of dyspnoea in patients with advanced cancer. *Palliative Medicine* 1997; 11:277-281.
10. Corner J, Planth H, Hern R, Bailey C. Non-pharmacological interventions for breathlessness in lung cancer. *Palliative Medicine* 1996; 10(4):299-305.
11. Galbraith S, Fagan P, Perkins P, Lynch A, Booth S. Does the use of a handheld fan improve chronic dyspnea? A randomized, controlled, crossover trial. *J Pain Symptom Management* 2010 May 39(5):831-8.
12. Scott RC, Besag FM, Neville BG. Buccal midazolam and rectal diazepam for treatment of prolonged seizures in childhood and adolescence: a randomised trial. *Lancet* 2002; 353:623-626.
13. Pellock JM. Use of midazolam for refractory status epilepticus in pediatric patients. *Journal of Child Neurology* 1998; 13(12):581-587.
14. *Symptom Relief in Terminal Illness.* 1998. Geneva, World Health Organization.
15. Hughes AC, Wilcock A, Corcoran R. Management of "Death Rattle". *Lancet* 1996; 12(6):271-272.
16. Rollins J., Bolig R., Mahan, C., 2005. Meeting Children's Psychosocial Needs, Across The Health Care Continuum, Pro-ED, USA
17. Wolfe J, Grier H.E., Klar N. et al. Symptoms and suffering at the end of life in children with cancer. *New England Journal of Medicine* 2000; 342(5):326-333.
18. Hockenberry-Eaton M, Hinds PS, Alcosr P, et al. Fatigue in children and adolescents with cancer. *J Pediatr Oncol Nurs* 1998; 15:172-182.
19. Collins JJ, Byrnes ME, Dunkel I, Foley KM, Lapin J, Rapkin B et al. The Memorial Symptom Assessment Scale (MSAS): Validation Study in Children Aged 10-18. *Journal of Pain and Symptom Management.* *Journal of Pain and Symptom Management* 2000; 19(5):363-367.
20. Collins JJ, Devine TB, Dick G, Johnson EA, Kilham HK. The measurement of symptoms in young children with cancer: the validation of the Memorial Symptom Assessment Scale in children aged 7-12. *Journal of Pain and Symptom Management* 2002; 23(1):10-16.
21. Bruera E, Faisinger R, MacEachern T, Hanson J. The use of methylphenidate in patients with incident pain receiving regular opiates: a preliminary report. *Pain* 1992; 50:75-77.
22. Bruera E, Miller MJ, Macmillan K, Kuehn N. Neuropsychological effects of methylphenidate in patients receiving a continuous infusion of narcotics for cancer pain. *Pain* 1992; 48:163-166.
23. Yee JD, Berde CB. Dextroamphetamine or methylphenidate as adjuvants to opioid analgesia for adolescents with cancer. *Journal of Pain and Symptom Management* 1994; 9:122-125.
24. Mather M, Good P, Cavenagh J & Ravenscroft P. Survey of bereavement support provided by Australian palliative care service. *Medical Journal of Australia* 2008, 188(4): 228-230

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